

MEDICINE AND SOCIETY

Who Are “Unrepresented” Patients and What Count as “Important” Medical Decisions for Them?

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Abstract

Unrepresented patients are hospital patients who lack decision-making capacity but have no advance directive and no one to serve as a legally authorized surrogate. An important first step in efforts to change the law and develop organizational policies that help respond to these patients' needs is determining which patients should be considered unrepresented and which aspects of hospital care should receive attention. This article proposes working definitions of *unrepresented* patient and *important* medical decisions based on the work of one statewide initiative, the Unrepresented Patients Project for Illinois.

Need for Policies Responsive to Unrepresented Patients' Needs

Everyone in health care wishes that every patient who cannot make important medical decisions has an up-to-date advance directive and a properly executed durable power of attorney for health care so that the patient's voice is as well represented as possible when important decisions need to be made. In the worst-case scenario, patients who lack decision-making capacity and for whom important medical decisions need to be made did not prepare an advance directive or other relevant documents about their preferences when they had decision making capacity and have no one to serve as their legally authorized surrogate. In the literature these patients are referred to as *unbefriended*, but the more common term now is *unrepresented*.

In most states, with only a few exceptions, there is only one legally authorized decision maker for such patients: [a guardian ad litem](#) is appointed by a judge to make medical decisions.¹ In most jurisdictions, however, this solution usually takes longer to implement than a treatment decision can be put on hold.¹ It is also expensive, and often guardians have heavy caseloads and know little about the patient.¹ In addition, unrepresented patients are typically cared for by physicians who rotate and whose views about proper goals of care and treatments for a given unrepresented patient can differ.

Ethical Issues in Medical Decision Making for Unrepresented Patients

Three major ethical concerns have been identified about how important medical decisions are being made for unrepresented patients in US hospitals.^{2,3} The first concern is about the impact of the existing legal mechanisms (in most jurisdictions) on the timing of those decisions, which will need to be made from the moment a patient is admitted until—if ever—a guardian *ad litem* is appointed who interacts with the patient's attending physician(s), reports to the court, and so on. The second major ethical concern is that unrepresented patients are cared for by hospitalists or resident physicians who rotate (hence the word "attending" above) and who might have differing views about what constitutes proper goals or care plans—which can and do change as they rotate—raising important concerns about the continuity of care and potential arbitrariness of the treatment decisions that are made. The third major concern is about the complexities of determining what is in the **best interest** of a person about whose life values we know nothing or next to nothing.

A number of state legislatures have begun to consider these issues,^{2,3} and, recognizing the absence of adequate legal responses, hospitals and health systems have also attempted to address these issues by means of organizational policies.⁴ One policy-oriented program with which the author is affiliated is the Unrepresented Patients Project for Illinois (UPPI), which was initiated by members of the Institutional Ethics Committee of the NorthShore University HealthSystem,⁵ a 4-hospital system primarily serving patients in Chicago's northern suburbs. As of this writing, UPPI has grown to include more than 100 individuals—hospital ethicists, ethics committee leaders, lawyers and administrators, and leaders of statewide organizations—representing 30 Illinois hospitals or systems and 15 other relevant Illinois organizations.

Defining *Unrepresented and Important*

With a view to proposing changes in the law or developing new organizational policies for the care of unrepresented patients, an important initial step is to determine precisely which patients should be considered unrepresented and which aspects of hospital care should be the focus of these efforts. The current UPPI working definitions of *unrepresented patients* and *important medical decisions* are offered below. These definitions are the product of research, email exchanges between UPPI members, and 3 in-person UPPI meetings held between April 2017 and April 2018. They are considered working definitions because adjustments and amendments are likely as specific organizational policies and changes in Illinois law are proposed.

Simply put, the goal of UPPI is to bring about changes in Illinois law to better address medical decision making for unrepresented patients. One change would be to enable court appointment of an in-hospital committee (or possibly individual) to serve as a legally authorized surrogate for an unrepresented patient (eg, as a guardian for health care) as soon as a patient is identified as unrepresented. Absent such legislative action,

hospitals or systems could enact policies that would enable such a committee (or individual) at least informally to partner with an unrepresented patient's attending physician(s) in determining the patient's best interest when important medical decisions need to be made for the patient and throughout his or her hospital stay (even as attendings rotate on and off).^{6,7}

Definition of unrepresented. UPPI currently defines an unrepresented patient as meeting 5 conditions:

A patient is Unrepresented who: (1) is facing an Important Medical Decision, and (2) is not capable of making an autonomous decision about this matter at the relevant time and is unlikely to recover this capacity before the decision needs to be made, and (3) has no advance directive and (4) lacks an identifiable substitute decision maker or legally authorized representative, and for whom (5) there is no other evidence from the patient's past or from other parties that is sufficient to support a reasonably conclusive judgment about what the patient would likely choose in the present situation if they were capable.

Regarding a patient's decision-making capacity (condition 2), this definition presumes that the usual ways of determining whether a patient is capable of autonomous decision making are sufficient.⁴ However, if changes in state law or probate court practices are needed, the language of decision-making capacity in relevant statutes in each jurisdiction—including relevant mental health statutes and directives—will have to be taken into account.

Regarding the lack of an [advance directive](#) (condition 3) and a surrogate (condition 4), this definition presumes the adequacy of current criteria for due diligence by hospital staff. For example, members of a social work department are often charged with determining whether a patient might have a relative or friend who is able and willing to serve as a surrogate decision maker or if there is an appropriate advance directive or other indication of what the patient would likely choose if capable. It is important to note that there are reasonable limits to such efforts, including how much effort must be expended in trying to persuade someone to take on the role and responsibilities of a surrogate. Nevertheless, efforts to answer these questions are not sufficient if they do not go significantly beyond what is immediately obvious and readily available.

Regarding lack of knowledge of the patient's preferences (condition 5), due diligence obviously requires that previous organizations, caregivers, acquaintances, and so on (if identifiable) be contacted to try to help determine what is known regarding the patient's reaction to previous treatments or what the patient would likely choose in the present situation if he or she were now capable. For if we can reasonably conclude what the patient would likely choose in a particular situation if he or she *could* choose—even if the patient lacks an advance directive and a surrogate—there is broad consensus in the US health care ethics community, the legal community, and the public that this option should be selected. Admittedly, this situation is extremely rare, but it deserves mention

because what the patient would likely choose if capable is a standard (referred to as *substituted judgment*) that typically outweighs the best interest standard.⁸

As mentioned, since reasonably conclusive evidence of unrepresented patients' preferences is lacking, those making treatment decisions are therefore left trying to understand what is in their best interest.¹ We might call such determinations *bare human values judgments*—judgments that are supposed to be based on what is valuable to or constitutes well-being for a human, whoever he or she is. It is well known that adults differ in what they consider valuable in life or what constitutes their well-being. Hence it is ethically problematic that whoever happens to be an unrepresented patient's attending physician may have to make important medical decisions alone—perhaps with personally chosen assistance—because there is no one to represent the patient. How best interest judgments ought to be made—which is widely debated in the bioethics literature⁶—is thus an important ethical consideration in caring for unrepresented patients, although rarely discussed in connection with this population.⁷

Definition of important medical decisions. UPPJ also proposes the following as a working definition of *important medical decisions*:

Important Medical Decisions are all the decisions about medical treatments and interventions that are neither emergent nor routine. Regarding emergent situations, the patient is presumed, both ethically and legally, to give implied consent for these. Routine medical interventions are those that do not require a formal act of consent because consent is taken to be implied when the treatment is in routine fulfillment of a plan of care that is based, in turn, on an already established determination of goals of care.

So defined, important medical decisions include decisions about treatments and interventions for which informed consent of either a patient or surrogate is required. It is important to note that the category of important medical decisions is not limited to decisions about instituting or ending life-sustaining treatments and other medical decisions at the end of life. In addition, this category includes decisions about determining or changing goals of care for a given patient and any decisions in which a plan of care to fulfill these goals is established or significantly changed. Obviously, an initial decision about goals of care for a patient is made soon after a patient's admission, even though there is often little explicit reflection on the reasons for and implications of such decisions because the focus is so often on determining a care plan. But since the latter depends upon the goals of care, determining goals of care is obviously an important medical decision, as are decisions to change goals of care or decisions to change a care plan that follows from those goals. Finally, important medical decisions include decisions regarding discharge for unrepresented patients who no longer need hospital care.

As noted, these definitions should be regarded as working definitions, because in any actual effort to formulate organizational policies or propose changes in state law,

existing definitions and policies will have to be taken into account. But the author offers them in the belief that they constitute a good beginning for better equipping the law, organizations, and caregivers to respond to the needs and vulnerabilities of unrepresented patients.

References

1. Pope TM. Making medical decisions for patients without surrogates. *N Engl J Med*. 2013;369(21):1976-1978.
2. Ind Code §29-3-8.5 (2017).
3. Concerning medical decisions for unrepresented patients, HB 16-1101, 70th Leg, 2nd Sess (Co 2016).
4. Pope TM. Unbefriended and unrepresented: better medical decision making for incapacitated patients without healthcare surrogates. *Ga State Univ Law Rev*. 2017;33(4):923-1019.
5. Ozar D. *Unrepresented Patient Project Illinois* [video]. <https://www.youtube.com/watch?v=4X1IHijhSz8>. Published October 8, 2018. Accessed April 25, 2019.
6. Lantos JD, ed. Best Interest. *Am J Bioeth*. 2018;18(8, theme issue):1-31.
7. Community Ethics Committee. Medical decision-making for unknown and unrepresented patients: a report submitted to the Harvard Ethics Leadership Group by the Community Ethics Committee. https://drive.google.com/file/d/OB-ehSSMbV_I6dm8xa1V5RWVINVU/view. Published March 2016. Accessed March 12, 2019.
8. Torke AM, Alexander GC, Lantos J. Substituted judgment: the limitations of autonomy in surrogate decision making. *J Gen Intern Med*. 2008;23(9):1514-1517.

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